



Genetic Discrimination

In recent decades, research in biology has gradually led to a better understanding of the human genome, its structure and its functions. At first, decoding the genome was a long and costly process; but then, thanks to major scientific breakthroughs, it became fast and affordable.

THE STATE AND POTENTIAL OF SCIENCE

Now, we can study the genome of an individual and carry out genetic tests. These tests are capable of predicting a person's risk for various diseases, including breast cancer and Alzheimer's, or an individual's response to a given drug. As a result, we can know in advance a person's likelihood of developing certain illnesses, making it easier to provide treatment in the early stages of the disease. The number of diseases that can be genetically screened is rising as genomics continues to move forward.



POTENTIAL PITFALLS

Unfortunately, the disclosure of a person's specific genetic information can become a source of discrimination. With genetic tests now more accessible and reliable than ever, concerns about discrimination are raising a number of issues, particularly in the area of insurance and employment. Genetic discrimination (GD) occurs when a person is excessively profiled or treated negatively based on genetic characteristics (suspected or proven). As with other forms of discrimination involving gender, ethnicity or disability, GD can be a source of exclusion. It can limit a person's social and professional opportunities. When this happens, a person's rights and freedoms may be compromised.



At the moment, very few empirical studies have been published on this topic. With the exception of specific single-gene diseases, such as Huntington's, it is not possible to determine with any certainty or accuracy the prevalence or severity of GD on a wide scale. However, the evidence does show that there is a widespread fear among the public of being subject to GD on the basis of genetic information. This fear exists in Canada, as well. Therefore, it is probably shared by Quebecers.

POSSIBLE SOLUTIONS

In April 2017, Canada adopted the Genetic Non-Discrimination Act (S-201) to prohibit and prevent GD and protect the privacy of individuals' genetic information. Québec has yet to adopt its own law on GD. In the policy brief "Genetic Discrimination in Québec: A flexible and proactive approach to address a complex social issue," the authors recommend that policymakers allocate the resources needed to conduct thorough legal analyses on the subject before arriving at a conclusion.

An assessment of the international landscape reveals that many countries have adopted laws and measures to protect citizens

from GD. Various approaches have been developed around the world and a status report on their effectiveness has been done. It indicates that since GD is such a complex issue, any legislative measure adopted in this regard should be accompanied by well-designed public campaigns that focus on the prevention of GD and address the actual risks to citizens.

European and American studies tend to show the importance of developing clear information practices and user-friendly access points to share information with the public regarding available protections and resources.

They also point to the limitations of substantive laws when it comes to addressing the challenges raised by GD, indicating the need to consider all other alternatives and/or complementary options before going forward with legislation.

A background image for the text block showing several hands in a light, semi-transparent style. The hands are positioned as if they are holding or supporting a glowing DNA double helix structure. The overall tone is scientific and supportive.

To learn more about the subject, consult the [policy brief](#) prepared by the Centre of Genomics and Policy of McGill University commissioned by Génome Québec.